



# Breaking Ground

## Leveling the Playing Field

By Jim Summerville

**T**he recent Winter Olympic games in Salt Lake City stirred the American imagination out of a season of heartbreak and grief. The Olympics remind us that everyone can share in the passion of athletic competition, not just paid professionals.

Amateur sports and recreational opportunities abound in Tennessee, including opportunities for individuals with disabilities. In fact, Tennessee athletes were proud to be part of the first Special Olympics games, held in Chicago in July, 1968. It was a small beginning. Only two sports, track and field and swimming, were offered, and only two countries, the United States and Canada, were represented.

### Special Olympics

Today, Special Olympics reaches more than 1.5 million youngsters and adults with mental disabilities in some 185 countries around the world. Twenty-two official sports and many more demonstration sports are offered throughout the year. There is no off season.

**Closer to home.** Special Olympics organized in Tennessee in 1971. By the end of the century, the program was

serving more than 15,000 athletes and every one of the state's counties. Twenty separate sports programs are offered, and training or competition takes place every month of the year.

Any resident of Tennessee, eight or older and having mental retardation or significant cognitive delays that require special services is eligible to participate in Special Olympics. There is no maximum age for participation.

In addition to traditional sports serving only these athletes, Special Olympics began offering a Unified Sports program in 1994. Unified Sports combines approximately equal numbers of athletes with and without mental retardation and of similar age and ability. These teams compete with other Unified Sports teams. Unified Sports increases the interaction of Special Olympics athletes in their communities. Used in public schools, Unified Sports enhances peer-tutor programs and other inclusion

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PHOTO BY PHILLIP HATCHER

Going for the gold—and getting it!

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efforts. Through Unified Sports, team members develop better sports skills, build new friendships, and reap the benefits that come from rigorous competitive play.

Unified Sports in Tennessee include

- Winter / Spring: ice skating (speed relay), basketball, and roller skating
- Spring / Summer: volleyball, tennis, powerlifting, bocce
- Summer / Fall: golf, softball, bowling, soccer

Special Olympics Memphis illustrates the variety of offerings in the original program. More than 1,500 individuals with mental retardation from Shelby and Fayette Counties train and compete in Olympic-style sports. These include

basketball, bocce, bowling, softball, tennis, golf, soccer, horseback riding, rollerskating, iceskating, downhill skiing, gymnastics, swimming, weightlifting, volleyball, and track.

**How to take part.** Anyone wishing to participate in Special Olympics must register with the area program in their community. (See the sidebar on page six on how to obtain this local contact information.) The process requires completion

**Off the sidelines.** Basketball is one of the most popular forms of wheelchair recreation.

of a form, health history, medical examination, and release statement. No fees are ever charged.

Athletes may qualify for local and area competition by training with an organized group, or may be trained by an individual volunteer coach, or even a family member. The athlete must train before competing in any sport.



## Basketball, track and field, and more

Easter Seals Tennessee wants to see the state become “the best place in the country for people with disabilities to live, learn, work, and participate fully in their communities.”

One of its programs, ABLE, helps assure that Tennessee will also be a good place to play. The acronym stands for “Athletes Building Life Experiences.” ABLE provides opportunities for children and youth with physical disabilities to participate in sports and recreational activities, which build strength, confidence, and social skills valuable in everyday life.

Recreational offerings at ABLE include basketball, track and field, tennis, fishing, bowling, water skiing, swimming, canoeing, and more. Criteria to take part are minimal. A youngster simply needs to be able to follow direction and instruction and independently propel a manual wheelchair. Other than that, a participant needs only the wish to strive for total independence and a desire to excel as an athlete.

ABLE Program Director Rick Slaughter says, “My goal is to teach as many children as possible and to introduce them to all types of wheelchair recreation. Through these activities children become completely independent and therefore learn a great life lesson: it’s not the circumstances that matter but what you do with the circumstances.”

Asked what he liked most about ABLE, young Luke Solimine responded, “It has helped me feel good about myself!” Basketball is Josh Anderson’s game, and he declares, “I know I can play like any kid plays, just in a different way.”

The parents of ABLE participants praise the program, too. “I have seen my child grow so much through sports,” says Tami Wing. “It is nice to hear him tell his friends about his games when they tell him about theirs. He’s no longer on the sidelines; he’s in the game.” Some parents have made friends and formed networks with others whose youngsters take part in ABLE. “It’s like an extended family,” observes Valerie Painter.

## Tennis

Nashvillian Beth Williamson recently founded Love Tennis specifically to introduce her favorite sport to people with special needs. A speech pathologist by training and a certified tennis instructor, Ms. Williamson sees her program as offering both therapy and fun.

Love Tennis will serve both children (from age 5 up) and adults who have a physical or mental disability, are chronically ill, or have behavioral or emotional problems. "This population is both more unfit physically and generally experiences greater difficulties with self-esteem" than the general population, she observes. Tennis, she believes, can definitely improve fitness and the learning of a new skill increases one's self-worth. The game is also a "mainstream social sport," she observes, and thus is another way for athletes with special needs to widen their world.

Ms. Williamson works to blend the therapeutic aspects of court play with whatever other health regimen her players might be pursuing. She also evaluates new players according to the skill levels they possess at the beginning and helps them set short- and long-term goals so that they and their parents or caregivers can objectively measure progress.

While the present class comprises ambulatory athletes, Ms. Williams plans to partner with ABLE's Rick Slaughter to incorporate wheelchair tennis in the near future.

## Martial arts

Some individuals who are unable to participate in contact or team sports are drawn to martial arts. At the Kum Sung Family Martial Arts School in Murfreesboro, people of all ages come to learn



(Left) Beth Williamson, Tennis Instructor and (Center) Chris Moran, Pediatric Physical Therapist

the kicks, balance, coordination, and concentration required for this sport. The physical techniques are combined with philosophical teaching to help the student develop and maintain a positive outlook, says Mari Cox, who co-founded the school with her husband Kevin.

The Coxes are parents of two-year-old Caden, who has Down syndrome. When they learned that Caden would be born with this disability, Mari says doctors encouraged them to leave Tennessee because of the lack of services. They decided instead to stay in the community

and create a program to help their son.

Caden has taken to martial arts, sometimes enjoying himself in a solo drill or teaming up with "kickin' buddies" like Remington Jent, two, of Gallatin. Recently the two encountered one another on the blue and yellow mat of the Kum Sung School. They sized each other up. Then Caden tackled Remington and both tumbled to the floor grinning.

**More than therapy.** "Kum Sung stresses positive thoughts," says Mari Cox. "We teach children, 'Be polite, be smart, be brave, be honest.'" Aside from the physical benefits, martial arts students find a sense of self-confidence that many did not have before. "One of the main goals here is to help them develop a 'yes-I-can' attitude."

Cindy Townsend, 31, of Antioch, has Down syndrome and a heart condition that causes circulatory problems, but she is an enthusiastic student at Kum Sung. She wears her uniform proudly. "It's been great for her," says caregiver Marie Turnmyre. "She listens to what Kevin and Mari tell her to do, and she does it. This gives her a sense of individuality, since it's not something everyone can do. It makes her feel like she has accomplished something."



Caden

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Still other agencies, associations, and advocacy groups sponsor recreational outlets for young people. *Breaking Ground* is indebted to the Tennessee Disability Information and Referral Office for the listing below:

## **West Tennessee**

### **Center for Therapeutic Taekwondo, Cordova**

Contact: (901) 309-1200  
Services provided: martial arts program for increased strength, range of motion, balance, and speed

### **Raymond Skinner Center, Memphis**

Contact: Eugene Harris, Director  
Phone: (901) 272-2528  
Age group: 5 years- adult  
Services provided: arts and crafts, swimming, and dance

## **Middle Tennessee**

### **Ables Recreation Association, Smyrna**

Contact: Nancy Scott, President  
Phone: (615) 220-9161  
Age group: 4-24 years  
Services provided: recreational calendar events year round, 1 week (5 day) summer camp

### **Down Syndrome Association for Middle TN, Nashville**

Contact: Sheila Moore, Director  
Phone: (615) 386-9002  
Age group: 8 years and up  
Summer camp: 14 years and up  
Services provided: recreational and social skills program once a month, summer camp

### **Empower Me Day Camp, Lebanon**

Contact: Michelle Harnsberger, Executive Director  
Age group: 5-21 years

Services provided: 8-week summer camp that promotes independence, self-esteem and physical and mental abilities

### **G.A.I.T.S. Inc. of Nashville**

Contact: Deborah Wray  
Phone: (615) 662-6268  
Services provided: Therapeutic horseback riding

### **Metro Parks and Recreation Department, Nashville**

Contact: Cathy Rader  
Phone (615) 883-2210  
Services provided: sports training program, year-round bowling league, Special Olympics adult day program- summer, summer recreation program

### **TOP Soccer Program, Franklin**

Contact: Jose Fernandez  
Phone: (615) 771-9577  
Age group: 4-19 years  
Services provided: soccer program to develop skills and increase physical activity

### **Southern STARRS, Lebanon**

Contact: Saranne Winfield, Program Contact  
Phone: (615) 453-2592  
Age group: 4-18 years  
Services provided: therapeutic horseback riding for children with emotional, behavioral, mental, or physical disabilities

### **United Cerebral Palsy of Middle TN, Nashville**

Contact: Greg Cox  
Phone: (615) 242-4091  
Services provided: sports program on a weekly basis

### **Williamson County Parks and Recreation, Franklin**

Contact: Vicki Pitner  
Phone: (615) 790-5719  
Services provided: adaptive aerobics, monthly adult social and recreational programs

### **Camp Will, Franklin**

Contact: Vicky Pitner  
Phone: (615) 790-5719  
Age group: 6-22 years  
Services provided: 7-week camp providing music, dance, recreational therapy, swimming  
Times of camp: 9 am-3 pm

### **Great Strides Therapeutic Riding Program, Shelbyville**

Contact: Kay Dennis  
Phone: (931) 685-1141  
Services provided: therapeutic horseback riding

### **Silver Bullets Ranch, Shelbyville**

Contact: Eva Carter  
Phone: (931) 685-9946  
Services provided: year-round therapeutic and recreational horseback riding

## **East Tennessee**

### **YMCA Camp Montvale, Maryville**

Contact: Markham Peykoff,  
Phone: (865) 983-9622  
Services provided: camps and summer programs

For additional information please go to the Pathfinder website at ***www.familypathfinder.org*** or call Carole Moore-Slater at 800-640-4636



## Therapeutic horseback riding

Saddle Up! is a therapeutic horseback riding program for children with mental and physical challenges, with its home in Franklin, Tennessee. Saddle Up! serves some 100 children, ages four to eighteen, most of them from Nashville or Williamson County. The disabilities represented include cerebral palsy, Down syndrome, spina bifida, pervasive developmental delay, autism, non-verbal disorder, seizure disorders, visual and learning impairment, learning disabilities, and others.

The mission of Saddle Up! is to provide these children with the opportunity to grow and develop through fun therapy with horses. The program seeks to improve a child's self-confidence, muscle relaxation, strength, flexibility, balance, and coordination.

**Gains to be had.** Executive director Dusty Knotts cites research that shows that therapeutic riding can bring physical, mental, and emotional rewards. Individuals with learning or mental disabilities are motivated by riding to increase concentration and patience. If a psychological or emotional disability is present, the relationship formed with a horse can help improve interpersonal relationships. And most riders seem to benefit from increased self-esteem and coping skills.

Eleven-year-old Michael Currie has been a Saddle Up! student for four years and has progressed to one of the program's more advanced horses, Ariel. Ariel requires more handling than some of the other horses. Michael's instructor, Angie Harris, feels that he has made great progress in his riding skills as well as speech skills. Michael, who used to sign all the time, now communicates verbally.

It's not just the youngsters who benefit from the program. Saddle Up! also provides parents with support, understanding, and even a little relief. Other important beneficiaries are the Saddle Up! volunteers, who help with virtually every part of the program. They instruct, review prospective students' health records, serve on the board, raise money, and even clean the stables. "Our volunteers usually start out on a limited

basis," says Dusty Knotts. "Soon they find themselves at the barn or a committee meeting every chance they get. They often tell us that working with Saddle Up! children is just the therapy they need!"

**Overcoming fears.** Rolling her wheelchair up next to the docile horse, Amy Kerin recalls her first days at the Shangri-La Therapeutic Academy of Riding (STAR), near Knoxville. The first thing she had to overcome was her fear of heights. "I've always liked horses, but that was from down here, not up there." Born with spina bifida, Amy had rarely ever towered above anything else.

Begun in 1987, the STAR program serves more than 70 students, most of them from the Knoxville area. Its founder, Lynn Klimas Petr, and her staff assess each applicant, then design a tailor-made program for that person's needs and goals. Ms. Petr has spent a lifetime around horses. She holds an undergraduate degree in special education and a master's degree in therapeutic recreation, both from the University of Tennessee. She has worked with a variety of children with physical and mental challenges, including brain injuries, muscular dystrophy, mental retardation, and autism.

STAR staff have witnessed transformations in their students, some subtle, some dramatic. One teen with a brain injury relearned how to lean over without support. Another child who had never spoken a word started gabbing in class about her horse.

## Accessible playgrounds

Lily's Garden is a playground in Nashville designed for children of all abilities. Some 70% of its equipment is accessible for youngsters with physical, sensory, and learning disabilities.

It is designed so that they do not have to leave their support equipment behind.



Lizzy B Solomon at  
Lily's Garden

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**High fives.** A Special Olympics track star accepts a teammate's congratulations.

Lynne Shaw, a resident of the neighborhood, realized the need for such a facility when her daughter Lily was diagnosed with spinal muscular atrophy. Ms. Shaw contacted Boundless Playgrounds, a nonprofit organization that provides technical assistance for groups all over the United States that take the lead in building accessible playgrounds.

Lily's Garden, which opened in the fall of 2001, is located at Blakemore and 24th Avenues, in Fannie Mae Dees Park. The location was chosen so that young patients at nearby Vanderbilt Children's Hospital could take advantage of the playground. It is also close to Harris-Hillman Special Education School and Eakin Elementary School.

According to Boundless Playgrounds, one in every ten children in most communities has some type of disability that excludes them from playing in traditional playgrounds. The group's goal is to help build an accessible playground in reach of every child during the next five years.

Two other Boundless Playground projects have been developed in Tennessee, at Camp Creek Elementary School in Greeneville and Siskin School in Chattanooga. ■

To obtain the name and contact information of your local Special Olympics director, contact

Special Olympics Tennessee, Inc.  
1900 12th Avenue, South  
Nashville, TN 37203  
Telephone: (615) 329-1375  
Fax: (615) 327-1465  
E-mail: [abolick@specialolympicstn.org](mailto:abolick@specialolympicstn.org)  
Web: [www.specialolympicstn.org](http://www.specialolympicstn.org)

You can reach Rick Slaughter, ABLE's program director at

ABLE, Easter Seals  
2001 Woodmont Blvd.  
Nashville, TN 37215  
Telephone: (615) 292-6640 or  
1-800-264-0078 (toll free)  
E-mail: [rslaughter@eastersealstn.com](mailto:rslaughter@eastersealstn.com)  
Web: [www.tn.easter-seals.org](http://www.tn.easter-seals.org)

To learn more about Love Tennis, contact

Beth Williamson  
4602 Mountain View Dr.  
Nashville, TN 37215  
Telephone: (615) 665-3344  
(615) 504-5333

For more information about martial arts for individuals with a disability, contact

Kum Sung Family Martial Arts  
1741 S. Rutherford Blvd.  
Murfreesboro, TN 37130  
Telephone: (615) 893-4567

The featured therapeutic horseback riding programs may be contacted as follows:

Saddle Up!  
1549 Old Hillsboro Road  
Franklin, TN 37069  
Telephone: (615) 794-1150  
Web: [www.saddleupnashville.org](http://www.saddleupnashville.org)

Shangri-La Academy of Riding (STAR)  
P.O. Box 22453  
Knoxville, TN 37933  
Telephone: (865) 690-9285  
Web: [www.kornet.org/staride/](http://www.kornet.org/staride/)

For more information about Lily's Garden, contact

Lily's Garden, Inc.  
392 Harding Place, Suite 200  
Nashville, TN 37211  
Telephone: (615) 367-6677  
Web: [www.lilysgarden.org](http://www.lilysgarden.org)

# Health Disparities Among People with Mental Retardation

By Jim Summerville

**O**n February 11, U.S. Surgeon General David Satcher released a report entitled *Closing the Gap: A National Blueprint for Improving the Health of Individuals with Mental Retardation*.

The blueprint comprises six broad goals and highly focused action steps to meet each one.

- **Goal 1: Integrate health promotion into community environments of people with mental retardation.** The report calls for more information support, and reinforcement of healthy lifestyles opportunities in places where individuals with mental retardation live, work, or play. Other recommendations include education and support in self-care and wellness and protection from occupational hazards.
- **Goal 2: Increase knowledge and understanding of health and mental retardation, ensuring that knowledge is made practical and easy to use.** The blueprint proposes collection of data on the utilization of health services by persons with mental retardation. The document also calls for an increase in the number of investigators trained in health and mental retardation research.
- **Goal 3: Improve the quality of health care for people with mental retardation.** The report recommends the development of standards of care and steps to ensure that the practice, organization, and financing of health care for these individuals promote improvement in quality of such services.
- **Goal 4: Train health care providers in the care of adults and children with mental retardation.** The document recommends integrating didactic and clinical training focused on this population into basic and specialized education of all providers.
- **Goal 5: Ensure that health care financing produces good health outcomes for adults**

**and children with mental retardation.**

The report recommends identifying a package of health care services that will produce good outcomes in maintaining health; studying ways to maximize health care purchasing power for individuals with mental retardation; and exploring ways to offset financial costs to providers and health services for meeting the specialized needs of patients with mental retardation.

- **Goal 6: Increase sources of health care services for adults, adolescents, and children with mental retardation, ensuring that health care is easily accessible for them.** The blueprint calls for an increase in the number of physicians, dentists, clinical psychologists, and allied health care professionals with training and experience in treating persons with mental retardation. It proposes various action steps to make access to care easier, including more community-based services and greater use of adaptive equipment and assistive technologies. ■

**Single copies of *Closing the Gap* are available from the National Institute of Child Health and Human Development (NICHD) Information Resource Center at**

**P.O. Box 3006  
Rockville, MD 20847  
Telephone: 1-800-370-2943  
E-mail:  
[NICHDClearinghouse@mail.nih.gov](mailto:NICHDClearinghouse@mail.nih.gov)  
Web: <http://nichd.gov/publications>**

**Additional copies of the report may be downloaded from the Surgeon General's web site:  
[www.surgeongeneral.gov/library](http://www.surgeongeneral.gov/library)**

# Child Care and Children with Special Needs

By Mark Wolery

**N**othing about having a young child with special needs or disabilities keeps a family from needing child care. Many of these families work or attend school and need responsible, caring people to watch the child during those hours. Research and program development activities are beginning to recognize this situation. In multiple national surveys, a majority of the responding child care programs report they enroll children with disabilities.

This finding is encouraging because full-day child care programs are wonderful places for providing early intervention services. Such programs often allow children to play for large parts of each day. Such times are ideal for teaching many important goals for young children with disabilities; for example, learning to share, to talk, to imitate peers, and to get along with those peers. Most class activities (such as story time, art, outdoor games, music) also are designed so children with different abilities can participate. A young child and an older child can listen to the same story. A child with disabilities and one without disabilities can do the same finger painting activity, ride in the same wagon, or bang the same drum.

Full-day child care programs also have important daily routines. For example, they have breakfast, lunch, and snack, which provide opportunities to work on feeding and eating goals. Because children attend for several hours each day, there is plenty of time to work on toileting goals. Thus, usual child care days are full of opportunities to teach the goals families and teams find valuable.

**Evaluating quality.** Children without disabilities learn more and are better prepared for school if they have attended a high-quality child care program. Further, researchers have

developed measures for evaluating the quality of child care programs. Some states, including Tennessee, are evaluating programs and giving different levels of licensure based on the quality of the program. Programs that do poorly with typically developing children are likely to do even more poorly with children who have disabilities.

Fortunately, we are learning about what constitutes high quality for children with disabilities in child care. The program needs to value inclusion of children with disabilities and value

being involved with families. The program must have someone or a team who can train and consult with the child care teachers and is available to them on a regular basis. The teachers must ensure the child with disabilities is participating in all the activities of the day and is learning from them. The team must help the teacher identify times of the day when each goal can be addressed and help them use the practices and procedures to allow the child to meet the goals. The teachers must ensure the child with disabilities interacts with (plays with, talks to, shares with, enjoys) classmates. This does not occur without careful planning or without concerted effort on the part of the teachers. The teachers must interact frequently with the child, be responsive to the child's words and activities, and be joyful—yet ensure the child learns. Finally, high-quality



Week of the Young Child will be celebrated April 7-13. See the top of page 9 for more details.



# Celebrating the Week of the Young Child

“Children’s Opportunities, Our Responsibilities” is the theme of this year’s National Week of the Young Child, celebrated April 7-13 nationally and locally. “Child Care and Children with Special Needs” by Mark Wolery recognizes that providing early intervention services within community child care programs is important for children and families.

Sponsored by the National Association for the Education of Young Children, the Week of the Young Child is a time to recognize that children’s opportunities are our responsibilities, and to recommit ourselves to ensuring that each and every child experiences the type of early environment—at home,

at child care, at school, and in the community—that will promote their early learning.

What you can do for young children:

- Register to vote.
- Learn more about candidates’ positions on the local, state, and national levels.
- Vote.
- Communicate your desires, needs, and opinions to policy-makers on the local, state, and national levels.
- Be certain that your child’s immunizations are current. Watch for children’s developmental milestones. If you have concerns about your child’s health and development, tell

your health care provider.

- Get a library card and use it frequently.
- Read to your child every day.

—Action steps from Nashville’s 2002 Celebration of Week of the Young Child

National Week of the Young Child:  
**[www.naeyc.org/woyc/default.asp](http://www.naeyc.org/woyc/default.asp)**

Nashville Week of the Young Child:  
**[www.vanderbilt.edu/kennedy/woyc](http://www.vanderbilt.edu/kennedy/woyc)**

Tennessee Early Intervention System  
1-800-852-7157  
**[www.state.tn.us/education/teishome.htm](http://www.state.tn.us/education/teishome.htm)**

inclusive child care classrooms must have materials and equipment the child with disabilities can access without help from others.

**Helping the teachers.** There are many challenges in child care that keep most programs from being high-quality classes for children with special needs. The classroom teachers often do not have any formal education for teaching children with disabilities; thus, they need frequent and readily available help from specialists. Often the specialists have to learn how to help other adults teach the child with disabilities. Young children—those with and without disabilities—need classes with relatively few children for each adult. Child care teachers, unlike public school teachers, often spend nearly all of their work week directly responsible for children. As a result, they have little time for planning, for consulting with experts, or for talking with parents. Programs must find ways to give classroom staff regular time each day for planning and training. In some programs (less so in high-quality programs) there is frequent staff turnover. When a good classroom staff

member resigns (often to take a higher paying job or one with benefits), the training and consultation have to be started again.

In summary, many families of young children with disabilities need child care. Child care classes can be ideal situations for working on children’s goals, but just being in a high-quality program is not enough. If children with disabilities are to meet their goals in child care, then their classes must be accessible, their teachers must have training, experts must be available to help the teachers, and the intervention must be planned and carried out in an individualized and effective manner. A legitimate goal of society is: Every family with young children (regardless of the child’s ability status) should have access to a high-quality, affordable child care program. These web sites have useful information about including young children with disabilities in child care: **[www.ccplus.org](http://www.ccplus.org)** and **[www.fpg.unc.edu/~inclusion](http://www.fpg.unc.edu/~inclusion)**. ■

**Mark Wolery, Ph.D., is a professor of special education at Peabody College of Vanderbilt University and is a John F. Kennedy Center Investigator. His research interests include the measurement of the quality of inclusive classes for young children with disabilities.**

# Tennessee Disability

TENNESSEE  
DISABILITY  
INFORMATION  
AND REFERRAL  
OFFICE



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## Servicios Para La Comunidad Latina Now Serving Spanish-Speaking Families

**T**he Tennessee Disability Information and Referral Office is now serving Spanish-speaking families, thanks to a new staff member, Solange Bishop, a bilingual social worker.

Originally from Colombia, South America, Solange has been a resident of Nashville for fourteen years. She graduated from Vanderbilt University and has worked as a counselor in several mental health agencies providing case management, information and referral, advocacy, and crisis management services.

Solange will assist in providing community information to callers in need of disability services

around the state. She will also be working in Hispanic communities with families in need of disability services who are unable to access

programs because of a language barrier. This outreach effort will be contributing to a significant need in our community and state.

Please help us spread the word about this important new service to reach more Tennessee families. And please let us know about people and places in your community—churches, restaurants and businesses, community centers, newspapers—who work with Spanish-speaking families. Our goal is to identify resources statewide. ■



Solange Bishop

## Statewide Disability Services and Supports Directories Available

**T**he 2001-2002 Tennessee Disability Services and Supports Directory is available in three volumes, East, Middle and West Regions.

Cost per directory is \$40, or \$80 for the set of three, plus postage and handling. To purchase and for additional information, call our office at 800-640-INFO (4636) for or complete an order form online at:

<http://kc.vanderbilt.edu/devents/order.html>



# Information & Referral Office

By Carole Moore-Slater

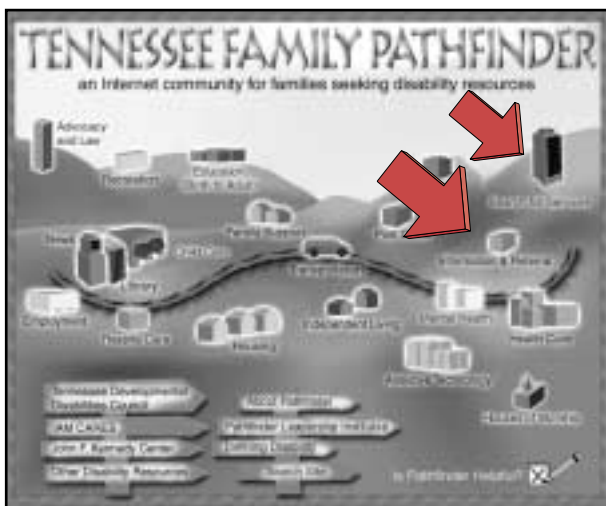
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## Directory Information Available On-Line

Now you can use the Internet to search the Tennessee Disability Information & Referral Office database of more than 1400 providers of disability services and supports. Go to the Tennessee Family Pathfinder web site:

**[www.familypathfinder.org](http://www.familypathfinder.org)** From the Home Page ("graphic version" or "text version") click on "Search for Services." You can search by county and type of service. A list is generated, with contact information and links to web sites, if the agencies have sites.

If you know the name of the service provider, you can access additional information about that provider, but keep in mind that you have to use the precise name (for example, Pacesetters, Inc.)



"Search for Services" links you to database of Tennessee services and supports.

"Information and Referral" links you to the Web page for the Tennessee Disability I&R Office.

If you need an explanation of any of the service categories, you can view definitions. The database uses terms recommended by the Alliance for Information and Referral Systems, the national organization for information and referral. We are using these national terms so that in the future we can exchange service information with other local, state, and national information and referral systems.

If you have any problems in searching for services through the Pathfinder site, please let us know. We welcome your suggestions.

## Contacting the I&R Office

The scope of information includes services and supports for persons with all types of disabilities, all ages. With the addition of a bilingual social worker, we will be collecting information to assist the Latino community with disability information. Let us know if you'd like to receive a packet of free I&R brochures to distribute. ■

## To contact Tennessee Disability Information & Referral Office

800-640-INFO (4636)

800-273-9595 (TTY)

615-322-8529 (Nashville area)

615-343-5737 (FAX)

[carole.moore-slater@vanderbilt.edu](mailto:carole.moore-slater@vanderbilt.edu)

[solange.bishop@vanderbilt.edu](mailto:solange.bishop@vanderbilt.edu)

[www.vanderbilt.edu/kennedy/tdirs.html](http://www.vanderbilt.edu/kennedy/tdirs.html)

**Carole Moore-Slater**

**is coordinator of the**

**Tennessee Disability**

**Information and**

**Referral Office,**

**a project of the**

**Tennessee Council**

**on Developmental**

**Disabilities, located at**

**the John F. Kennedy**

**Center for Research**

**on Human**

**Development,**

**Vanderbilt University.**

# Vote and Have Your Say in 2002

By Carole-Moore Slater

**I**t's an election year in Tennessee, and state politics has not seen such an interesting season in a long time. There will be open races for Governor, a U. S. Senator, and several new U.S. Representatives.

The election contests that will most affect services and quality-of-life issues for Tennesseans may be those closer to home. In municipal and county elections, voters will choose officials such as City Council members and County Commissioners who determine budgets for public social service agencies. Elsewhere on the ballot will be listed candidates for the General Assembly, our state legislature, where policies, programs—and funds—that affect disability concerns are decided.

It is a critical time to be voting in Tennessee. Yet, the Tennessee Disability Coalition estimates that there are more than 53,000 unregistered voting age people with disabilities.

How do you know if you're eligible to vote? It's easy: the only requirements are that you be a U. S. citizen, reside in Tennessee, and be at least 18 years old on or before the date of the election. Those dates in 2002 are

## **May 7 Local Primaries**

## **Aug. 1 Party Primaries**

Party nominees will be chosen for the offices to be filled in November, below. This is also the date of local general elections, filling county and municipal offices.

## **Nov. 5 State General Election for**

- Governor
- U.S. Senate (seat vacated by Sen. Fred Thompson)
- U.S. House of Representatives
- All seats in the Tennessee House of Representatives
- Some seats in the Tennessee Senate

Here are some commonly asked questions about participating in the electoral process.

**Do I have to register if I want to vote?** Yes, provided you have never been registered to vote in Tennessee. If you have previously registered but have since changed addresses, you must re-register.

If you are a woman who married and changed your name, you are not required to re-register, but you must notify the county election commission of your new name.

**When do I have to register?** You may register at any time but you must do so not later than 30 days before the election in which you wish to vote.

**Where do I go to register?** You can register at your local County Election Commission office, or you may apply to register when you apply for a driver's license. The address and telephone number of the County Election Commission can be found in the county government listings of your telephone directory. You can also register on-line at [www.state.tn.us/sos/election/county.htm](http://www.state.tn.us/sos/election/county.htm)

**What obligations do local governments have to meet the needs of voters with a disability?** In federal, state, and local elections, county election commissions have legal obligations to meet the accessible needs of voters with disabilities.







The federal Voting Accessibility for the Elderly and Handicapped Act of 1984 requires polling places across the United States to be physically accessible to people with disabilities in federal elections. Where no accessible location is available as a polling place, election officials must provide an alternate means of casting a ballot. This law also requires states to make available registration and voting aids for voters who are elderly or have disabilities, including information by telecommunications devices (TDD/TTY) for those who have severe hearing loss. Under the Americans with Disabilities Act, a county has a legal obligation to conduct elections in a manner that enables individuals with disabilities to vote.

**For more information contact:**

**Voting Section  
Civil Rights Division  
U.S. Department of Justice  
P.O. Box 66128  
Washington, D.C. 20035-6128  
(800) 253-3931 (voice/TTY)**

**I have a disability, but I want to vote. What else do I need to know?** You have the right to be assisted at the polling place by a person of your choosing. Another option is to vote by absentee ballot. You may choose to file a physician's affidavit attesting to your disability when you register. You will then automatically receive an absentee ballot for every election.

**How does a person vote if out of town on Election Day?** Approximately a month before an election a person can vote at the county election commission office or at any one of the other early voting sites. Any registered voter

may vote at any of the early voting sites in the county regardless of where the voter lives. Call your county election commission for places and times for early voting. Another option is to request an absentee ballot from the election commission in person, by mail or by fax. If the request includes your name, address, Social Security number, the address outside the county to which you want the ballot to be mailed, the election in which you wish to vote, and the reason you must vote absentee, it will serve as an official application for a ballot. You must mail your absentee ballot in time to reach the commission office on or before Election Day.

**Where can a person get more information about registering and voting in Tennessee?** Contact your local county election commission office. You can also obtain more information on-line at [www.Tennesseeanytime.org/main/citizen/voting.html](http://www.Tennesseeanytime.org/main/citizen/voting.html)

The existence and funding of programs serving individuals with disabilities will be decided by who gets elected to public office all across our state. Register, and study the stands that candidates take on issues that matter to you. Then make your vote count. ■

Thanks to The Arc of Tennessee, Davidson County Election Commission, Tennessee Disability Coalition, and the League of Women Voters of Tennessee for information used in this article.

*Carole Moore-Slater  
is coordinator of the  
Tennessee Disability  
Information and  
Referral Office,  
a project of the  
Tennessee Council  
on Developmental  
Disabilities, located at  
the John F. Kennedy  
Center for Research  
on Human  
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Vanderbilt University.*

# Traveling by Chair?

## Patience is the Key to Survival

*By Andrea Cooper*

**W**hen I vacationed in England as an ambulatory 10-year-old, my dad gave me a smart piece of travel advice. He said that if I was going to be a traveler, I had to roll with the punches and go with the flow. That's good advice for any traveler, but it's invaluable to those who travel with wheelchairs.

I have used a power wheelchair for five years, and I have had good luck taking it on a few trips until last November. Ironically, it was during a trip to attend a National Association of Developmental Disabilities Councils (NADDC) conference that my husband Matt and I learned first-hand that accessible travel tops the issue list for persons with disabilities. The Tennessee Council made tentative airline and hotel reservations for me, as it had done before, then I called the airlines myself to make sure that they understood the needs of my power chair. When I explained to the special assistance agent that I would be traveling with the power wheelchair, he asked what type of battery the chair contained. He was satisfied when I told him that the batteries were sealed gel cells that would not leak. Regrettably, I failed to remind him to check the height of the cargo hold in each aircraft on which I would travel.

The American Airlines agent at baggage check-in insisted that my batteries have a label reading "nonspillable" or they must be removed, which for my chair, means the chair must be disassembled. My batteries were labeled "sealed gel cell." When I first started flying with the chair, I asked my wheelchair mechanic for a lesson on how the chair was assembled and connected. He had reviewed the connections with me, but warned that under no circumstances should my chair be taken apart or have the batteries removed due to the complexity of the features of my chair. This is why I purchased sealed gel cell batteries.

Having read (and nearly memorized) the Air Carrier Access Act (ACAA), I suggested that the agent check with the Complaint Resolution Officer to settle our semantic dispute. A supervisor appeared, reviewed the battery labels, and declared, "Oh yes, this means 'nonspillable.'" The agent continued tapping at the computer keyboard and hit another stop. The aircraft, albeit a jet, did not have a cargo hold at least 45 inches high to accommodate the stowage of my chair in the upright position. I took a deep breath. Getting angry was not going to encourage this agent to help me. He promptly exchanged our tickets, booking us on an alternate route with larger planes.

**More patience required.** We notified our travel companion, Wanda Willis, the Council's Executive Director, that we were no longer on her flight. We joined her at her gate to wish her bon voyage and to make sure that she had our new travel plans in order to adjust our ground transportation and hotel reservations in Reno when she arrived. Suddenly, an American Airlines agent rushed towards Matt and pulled him aside with the story that prior hazardous material violations had put the company on probation with the FAA, so they did not want to take a chance with a battery that did not say exactly "nonspillable." Once again, patience prevailed. We suggested that American Airlines purchase tickets for us on another air carrier that did not have a problem with the language.

When we arrived in Minneapolis on Northwest Airlines to connect to Reno, there was an ominous delay in my dismissal from the plane. I thought that the front row, first-class seating would accelerate the deplaning process. Matt finally returned to my airplane seat with the frustrating news that ground crew had ripped the

main cable from the joystick to the motor of my chair. It was inoperable, and I feared, not easily fixed. Fortunately, I carry the 800 number of my wheelchair manufacturer so that I can obtain a list of qualified repair centers anywhere in the country. Unfortunately, this 800 number operates only during business hours on Monday through Friday, and we had arrived at 7:30 p.m. on Sunday evening. Similarly, medical supply companies in Minneapolis were closed. I was stuck, and this was no time for hasty decisions.

**Seeking resolution.** The Complaint Resolution Officer (whom I asked the flight attendant to call as soon as I learned of the damage) intelligently offered me a blank slate on which to draw my plans at Northwest's expense. I did not want to leave my chair or continue on my journey until I knew the time frame for repairing my chair. If I hastily continued to Reno, I may have been stuck there without even a rental power chair. I had few options, but I had learned to go with the flow, so I itemized my desires for the Complaint Resolution Officer. First, I wanted my luggage pulled immediately from the plane. In case our checked luggage had followed us to Minneapolis, I could stay more comfortably overnight with the additional pieces of medical equipment that I had checked. Second, I wanted accessible ground transportation to a hotel close to the airport with an accessible room so that I would have somewhere comfortable to stay until I could make telephone calls in the morning. Third, I wanted the option to decide the next day whether Northwest would fly us to Reno or return us home to Nashville based on my contact with medical companies. Northwest granted every request and included vouchers for meals and subsequent free travel. They could not provide, however, a decent manual chair for me to use overnight. The best one that they could find had broken brakes and foot pedals that were too long to support my feet properly.

I was thankful that Matt had packed two critical things that were not in my suitcase: a cellular phone and a supply of cash in small bills. As soon

as I was able to call the manufacturer of my chair, I began leaving messages with authorized repair centers in Minneapolis. Within three hours I was able to make arrangements to have my chair examined in Minneapolis and to reserve a rental chair in Reno.

**"Wheelchair Survivor?"** Cash was equally indispensable since the need for additional help generates the obligation of tipping service people. I was at the mercy of a manual chair that someone had to push, and we had all of our checked and carry on luggage, as well as an additional bag to carry for my power wheelchair accessories. Thus, Matt and I needed shuttle drivers, bell persons, and sky-caps to help us. So, we moved from gratuity to gratuity to make our way back to the airport.

Progress resumed once a local medical company located a joystick and cable to loan to me while the company repaired mine. My independence was restored, our luggage was checked, and we were once again on our way to Reno. We arrived around midnight, which was 31 hours after our originally

scheduled arrival. Amazingly we were still resilient enough to roll with the punches. The next punch came with the hotel shuttle service when the driver loaded me on the wheelchair lift only to find that it would not rise. Once again, we gathered our things and backtracked. We telephoned the hotel from inside the airport rather than rely on the departing shuttle driver's promise to send a cab for us. We confirmed with the hotel manager (and noted her name) that a wheelchair accessible cab had been called and that the hotel would pay the fare. Once we arrived at the hotel, we spent our last ounce of patience insisting that our room be vacant, accessible, and, ultimately, free. The hotel, despite Wanda's instructions, failed to keep our reservation for an appropriate room.

On the day of our return trip, we arrived at the airport extra early. As our plane pulled away from the gate, it seemed that we had made it out of the woods on our "Wheelchair Survivor" adventure.



Andrea Cooper

**More to come.** The plane stopped, reversed direction, and returned to the gate. The adventure was not over. The plane had a mechanical problem, and an estimated thirty-minute delay turned into a cancellation when a replacement part could not be located on the West Coast. I laughed until tears filled my eyes as the gate agent booked us on a flight for the next day and doled out taxi vouchers, meal coupons, and hotel reservations. I was not patient; I was delirious.

Our one-night free vacation ended at two the next morning when we had to start the morning ritual, including repacking, in order to get to the airport for a 6:00 a.m. flight. Given our delays and multiple room changes, Matt had packing down to a few swift movements. We returned to the airport and continued through the motions in a fog until we got to Minneapolis. Just before our departure to Nashville, a flight attendant approached my seat. I recognized her expression and prepared to rate her news on my mental disaster scale. The ground crew was having difficulty fitting my chair in the cargo hold. Since we had taken my chair on the same aircraft (DC-9) on the way to Reno, this information did not approach disaster level. I asked the flight attendant to remind the ground crew that mobility devices take precedence over other pieces of

cargo, and that my chair was not to be disassembled or stored in any manner other than the upright position. I had already included this information on the handling instructions that I had posted all over my chair. The flight attendant agreed, relayed the message, and assured me that the problem was solved just as the plane pushed away from the gate.

Our flight arrived on time in Nashville. Matt rushed to the door of the plane to meet my chair. He returned with the infamous, frazzled look. Despite our specific instructions, the Minneapolis ground crew had disassembled my chair, removed the batteries, and stored my chair on its side.

The Nashville crew delivered the chair in pieces to my husband and asked, “You can get this back together, can’t you?” Just like a rerun of a bad movie, I insisted that the crew contact the Complaint Resolution Officer, and I telephoned my wheelchair mechanic to put him on notice that I might need help with my chair. Fortunately, with Matt’s help and upon his insistence, the crew was able to reassemble the chair, not perfectly, but functionally.

When I returned to my wheelchair, the Complaint Resolution Officer delivered the findings of his cursory “investigation.” His position was that there was more than one model of DC-9, so my chair may have fit upright on an earlier DC-9 flight, but this particular model did not have a large enough cargo hold to accommodate my chair. He offered no response when I asked him for the basis on which the airlines disregarded the ACAA by not checking the size of the cargo hold or informing me of the problem before disassembling my chair against my express instructions. I then confirmed that the airline would pay any labor costs for my wheelchair mechanic to reassemble the chair correctly. I already had obtained the airline’s commitment to pay for the labor to exchange my repaired joystick with the loaner and for the postage to ship the borrowed part back to Minneapolis. Additionally, I offered to send to the Complaint Resolution Officer a copy of the complaint that I planned to file with the Department Of Transportation.

There were enough violations of the ACAA during my trip to use my story as a law school exam. The Act contains rules for airlines about service for travelers with disabilities, and it provides recourse for violations of those rules. Nevertheless, the Act cannot provide survival skills when things go wrong. Preparedness can ease the inconvenience of travel dilemmas, but patience is how one survives. Keeping a clear head as the punches are coming will help a traveler keep options open as problems arise. For better or for worse, travel is an adventure, and sometimes even if a traveler is in the right, she must go with the flow until she is home. ■

*Andrea Cooper*  
is a member of the  
Tennessee Council  
on Developmental  
Disabilities and a  
frequent contributor  
to *Breaking Ground*.



# Leigh Gilliam Remembered

*By Joe Swinford*

I was fortunate to have worked with Leigh Gilliam for the past three years. Leigh worked with us in the Department of Mental Health and Developmental Disabilities Office of Consumer Affairs as a consumer advocate. Though many of the folks who contacted our office had a different disability than she, she had a unique ability to connect at a basic human level with the struggles the person would be going through. Most of the time she was faced with helping some who had fallen through the cracks in the system or who were so frustrated by the system that they felt that they were at the end of their rope.

At times Leigh would spend hours on the phone with someone, just helping them get past the pain and anger they felt about the system in order to get down to the need they had and find a way to help get the system to respond to that need. Along with the compassion, she could be tough if the situation called for it. She refused to accept pat answers or allow decision makers to get sidetracked by administrative issues. She would always look to the bottom line, which was helping make a difference in the lives of the people we serve. That included not only making a difference for that one person, but also making a change in the system to see to it that others did not have to face that problem.

Leigh set an example to us all of how to overcome the challenges we face in life. She also set an example of how to challenge stigma and an unresponsive system with what one advocate, in describing her, called “a quiet determination” to stand up for what is right. Although she is gone physically from us, the legacy she left will light the way for all of us who advocate within the disability community. ■

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Joe Swinford is director of the Office of Consumer Affairs at the Tennessee Department of Mental Health and Developmental Disabilities.

*By Kevin Wright*

When I served as the Director of the Partners in Policymaking Leadership Institute and Youth Leadership Forum, I had an opportunity to meet many advocates. One of the most passionate of those advocates was Leigh Gilliam. While Leigh is no longer with us, her advocacy will live on in the lives of those she helped become advocates for themselves.

Leigh had the unique ability to make an instant connection with you. Whether you were a stranger or friend, you felt as if you could tell her your story and she would make everything better. She was not the most vocal member of her



Partners class, at least not at first. Rather, she seemed to prefer to listen. After she was satisfied that she understood your challenges, she would work hard at finding an answer. She worked even harder at helping you find an answer. Leigh truly cared, not just about your issue, but about you.

Her caring personality was never more evident to me than when she served as resident assistant at the first Tennessee Youth Leadership Forum. In that role, she supported the housing needs of the delegates. One of her most important yet under-appreciated duties was to monitor the dorm halls well past 1:00 a.m. Her assignment was to ensure that the delegates didn't cross the line she had created with her chair in the middle of the hall separating the young men from the young women. She would hold fast to her post until she was sure that everyone was well off into dreamland. Why would someone force herself to disobey her internal sleep clock? She did it because she cared.

Leigh will be greatly missed in the disability community. She will be missed by her family and friends. She will be missed by me. ■

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Kevin Wright is director of the Tennessee Technology Access Program.

# 18 Letters to the Editor

## Ms. Wheelchair Tennessee—How Representative Is It?

*To the Editor:*

*I just finished reading the recent **Breaking Ground**—a wonderful publication as always!!! I am, however, a little uncomfortable with the article about the Ms. Wheelchair competitors. The author claims that the titleholders are out in the community educating the "public regarding the dignity, productiveness and basic value or people with disabilities." Unless other Ms. Wheelchair titleholders have attributes that don't include a B.S. in civil engineering, being gifted, or performance accolades, I submit that the titleholders represent a small segment of the population of people with disabilities. I do not mean in any way to diminish or minimize the accomplishments of the current titleholders, but if this is the standard that*

*represent, then the public will be sorely disappointed when they meet my daughter. The eligibility criteria for the competition alone, narrow the "constituency" that can be represented.*

*—Joanne Bregman*

*To the Editor:*

*Thank you for sharing Joanne's comments. I shared her comments with a current titleholder, who responded, "Ms. Wheelchair Tennessee does indeed focus on issues surrounding mobility impairments simply by virtue of its attributes (just as People First focuses on cognitive issues). We are all working together to try to change the public's perception of people who are 'different.'"*

*Another former titleholder explained: "A spokesperson is chosen to educate and raise*

*awareness, not to say everyone with a disability is alike. Miss America contestants speak out about disabilities and many have none. They are still raising awareness."*

*Ms. Wheelchair Tennessee, like any other representative for a constituency, is selected based on her ability to articulate the needs of persons with disabilities, to teach others how to be self-advocates, and to advocate on behalf of those who are less capable of making their needs known. This program seeks female representatives who have demonstrated leadership in overcoming architectural and attitudinal barriers. Hopefully, the lessons learned and shared by our titleholders will have a carryover effect for all persons, regardless of gender or disability.*

*—Andrea Cooper*



Janet Simons, Middle Tennessee regional director for the state Division of Mental Retardation Services, recently spoke with a group of self-advocates. This was one of a series of gatherings sponsored by The Arc's Real Lives staff.

## "Shifting the Power" Training Gets Under Way

**T**he ARC of Tennessee "Real Lives" staff are excited about the train-the-trainer sessions for self-advocates that began this spring.

A four-person training team from the University of North Carolina at Chapel Hill will be working with eighteen self-advocates from all three regions of Tennessee to enhance self-advocacy skills among their peers statewide.

The three-day train-the-trainer sessions should produce eight or nine two-person training teams, who will strive to enhance the self-advocacy skills of 150 peers over the coming year.

# Disability Community Loses a Great Legal Advocate

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By Shirley Shea

**G**ary Buchanan, noted Nashville attorney who specialized in disability law, unexpectedly passed away on

January 9, 2002. At the time of his death, he was the Senior Staff Attorney with Tennessee Protection and Advocacy (TP&A). With an undergraduate degree from Middle Tennessee State University, he graduated from the Duke University Law School. In addition to his legal advocacy

work at TP&A, Gary previously was counsel for The Arc of Tennessee and in private practice.

Gary was a leading special education litigator within the protection and advocacy system and earned a national reputation as such. His precedent-setting legal victories have

assisted attorneys across the nation as they defend the rights of students.

Described as "a gentle giant" by his wife Linda, Gary was truly a



Gary Buchanan

Southern gentleman whose intelligence was matched by his sharp wit. Forceful in court, he gained respect from his opponents.

Family, friends, colleagues, and individuals with disabilities and their families will always remember the dedication that Gary demonstrated throughout his professional career. We are grateful to have had the opportunity to work with him as a colleague and know him as a dear friend. ■

Shirley Shea is executive director of Tennessee Protection & Advocacy, Inc.

The ARC of Tennessee has collaborated with the Council on Developmental Disabilities, UT Boling Center on Developmental Disabilities, People First of Tennessee, UT-TIE, and the Memphis Center for Independent Living on this project.

If you are aware of an agency or organization who would like to host a "shifting the power" series of training, please contact The Arc of Tennessee at 1-800-835-7077.

The "Real Lives" project is funded through the Division of

Mental Retardation Services and the following training or assistance can be obtained by contacting The Arc of Tennessee office.

- Training on Self-Determination
- Training on Self-Advocacy
- Assistance with New Agency Start Up
- Assistance with Understanding the Division of Mental Retardation System
- PATH Planning
- Advocacy within Circles of Support ■

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## About the Council:

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of systems change.

The editor will consider for publication original contributions, including news and feature stories, short fiction, poetry, artwork, and photographs but reserves the right to edit or decline publication. Brief letters to the editor are also welcome. Opinions expressed in any published matter are the author's and not necessarily those of the Tennessee Council on Developmental Disabilities or its staff.

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